PLACEMENT POLICIES FOR SCHOOL CHILDREN AFFLICTED WITH COOLEY'S ANEMIA IN THE UNITED STATES

A Field Report

Presented to

The Graduate Division

Drake University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science in Education

---

by

Virginia Victoria Mazzei

August 1964

PLACEMENT POLICIES FOR SCHOOL CHILDREN AFFLICTED WITH COOLEY'S ANEMIA IN THE UNITED STATES

by

Virginia Victoria Mazzei

Approved by Committee:

Louis F. Hegge, Jr.
Chairman

Earle T. Campbell
Dean of the Graduate Division

TABLE OF CONTENTS

PAGE

CHAPTER I

INTRODUCTION

Each year the teacher faces his or her own particular group hoping to provide the best possible learning situations for each individual child. Sitting in the room will be children of varying mental and physical abilities. This study will focus attention on the child with limited physical stamina and how we can best make school a pleasant and profitable place in which he can learn. The child with Cooley's anemia or Thalassemia major is such a child.

I. THE PROBLEM

Statement of the problem. There is a growing need to provide parents and teachers with information as to what kind of schools children with Cooley's anemia should attend. This study has attempted to gather data as to the kinds of schools they are attending and make recommendations as to the various ways the time spent in school can be used most profitably.

Purpose of the study. It was the purpose of this study (1) to determine how many children in the United States have this type of anemia; (2) to find how many children are attending school in regular classrooms; (3) to ascertain

what measures have been made to accomodate these children in either school.

Need for the study. Although Cooley's anemia is a rare type of disease, through the establishment of the Cooley's Anemia Blood and Research Foundation for Children, Incorporated, many more cases have been found than were previously known. Parents of these children face a problem of where to educate them. Tenny said:

> Relatively few school systems provide special class facilities for physically handicapped children and only a small percent of such children are cared for in special day or residential schools. Evidently a large number of children with more or less serious handicaps either are receiving no educational opportunities at all or are in classes with normal children. In the latter case, most teachers lack the necessary training to take care of the atypical children or they are so heavily loaded with large classes that little time is available for meeting the needs of these children. To overcome these difficulties two steps seem necessary: (1) to increase the number of special classes, and (2) to increase the knowledge and skill of regular teachers so that they may care more adequately for those atypical children who are enrolled in their classes.[1]

There is a lack of information for parents and teachers on how to deal constructively with these children. Parents are anxious to know about understanding the circumstances and difficulties of these children. As Lee and Lee stated:

---

[1]John W. Tenny, "Caring for Physically Handicapped Pupils in Regular and Special Classes," The National Elementary Principal, XIX, No. 6 (July, 1940), 483.

> A normal amount of sympathy and understanding of others' troubles, sorrows and joys is a fine trait. When it is present in excess, a child presents an example of maudlin sentimentality or hyper-excitability. Such children should have a minimum of emotional stimulation and the kind calming hand of a teacher to help bring the situation to a more reasoning basis.[1]

It is hoped that this study will be an aid for teachers and parents in knowing how much or how little to expect from this child.

Basic considerations. Cooley's anemia or Thalassemia major as described by Lichtman, is the name commonly used to describe the severe form of an hereditary disease of blood. It is also called Mediterranean anemia, target cell anemia, erythroblastic anemia and familia microcytic. This disorder occurs most commonly in individuals whose ancestors were natives of the countries surrounding the Mediterranean sea. In the United States most of the patients are of Italian descent, especially Sicilian. Those of Greek, Turkish, Southern French, and North African origins are also more susceptible.[2]

---

[1] J. Murray Lee, and Dorris May Lee, The Child and His Curriculum (New York: Appleton-Century-Crofts, Inc., 1940), pp. 37-38.

[2] Herbert C. Lichtman, "Cooley's Anemia" (New York), p. 1, (Mimeographed.)

II. DEFINITION OF TERMS

The following definitions are of terms used in the report:

Thalassemia major or Cooley's anemia. Thalassemia major or Cooley's anemia is a severe type of anemia that is inherited according to Mendelian laws which occurs in a child born of parents both of whom must be carriers of the trait.

Thalassemia minor. Thalassemia minor is a less severe type of anemia that is inherited from one parent who is a carrier of the trait.

Special schools. A special school is any school which educates any kind of physically handicapped children or one which has a room set aside especially for children with limited physical stamina.

III. MEDICAL BACKGROUND

Anemia is a deficiency of red blood corpuscles, hemoglobin or both. It may occur following infectious diseases, after a hemorrhage, or from absorption of toxins from foci of infection, intestinal obstruction, chemicals, congenital causes, or due to poor nutrition and iron deficiency. It may be a temporary condition or a permanent one. Anemia

which is due to poor nutrition and iron deficiency is less serious and may be remedied by diet or Vitamin B_{12} injections. Aplastic, primary or pernicious and secondary anemias are the more severe types of anemia. The symptoms for these types are about all the same: shortness of breath, palpitation, malaise, headache and edema of ankles. Some of the more serious types of anemia are treated by administering blood transfusions the entire life of the patient.[1] Another serious type of blood disorder that is treated similarly to the above anemias is Leukemia. However, Leukemia differs from Cooley's anemia in that the white corpuscles rather than the red ones are affected. This disease is characterized by a great excess of white corpuscles with hyperplasia of the spleen and the lymphatics and in the bone marrow.

Etiology of Thalassemia. Cooley's anemia is the name commonly used to describe the severe form of an hereditary disease of the blood. Cooley, an American physician, described this as a separate and specific type of blood disease in 1925.

This disorder occurs most commonly in individuals whose ancestors were natives surrounding the Mediterranean sea. In the United States, therefore, most of the patients are of Italian descent, especially Sicilian. Those of Greek, Turk-

---

[1]Clarence Wilbur Taber, Taber's Cyclopedic Medical Dictionary, Revised Sixth Edition (Philadelphia: F. A. Davis, 1955), p. A-51.

ish, Southern French and North African origins are also more susceptible. There are a few cases found in among the Chinese. Wintrobe reported:

> Until 1942 less than 100 cases of Cooley's anemia had been reported. Later surveys of persons of Italian descent in Rochester, N. Y. revealed the severe form of the disease occurring once in 2,368 births and the lesser anomaly once in each 25 persons.[1]

Individuals with Thalassemia minor have a normal life span and enjoy normal health, whereas individuals with Thalassemia major may succumb to the disease in a matter of one or two decades. Lichtman has stated:

> Thalassemia major usually becomes manifest during the first year of life. Both sexes are equally affected. The earliest signs may be pallor of the skin and musous membranes, and sometimes a slight yellow coloration of the whites of the eyes. There are several defects which lead to anemia. There is a reduction on the rate at which the red blood cells are formed in the bone marrow and released to the blood vessels. Those cells that are produced are defective in that they do not survive in the blood for more than one-third to one-half of the normal span of red cells, which should be about 90 to 120 days.[2]

Sometines there are complications which develop in certain individuals which further reduce the rate of blood cells. The greatly enlarged spleen may be the cause of this additional hindrance. As a result of the chronic state of anemia, the children with this disease are greatly handi-

---

[1]Maxwell M. Wintrobe, Clinical Hematology (fifth edition; Philadelphia: Lea and Febiger, 1961), p. 701.

[2]Herbert C. Lichtman, "Cooley's Anemia" (New York, 1963), p. 2. (Mimeographed.)

capped. Bone growth is poor, therefore, they are usually small for their age.

> Because of abnormalities of the bone marrow, there are alterations of the skull and other bones so that a characteristic facial expression is found which gives many of these children the appearance of being related.[1]

The bones are quite fragile and fractures are quite common. The anemia causes easy fatigability and a lack of pep and energy. There is no particular increase in susceptibility to infections. No type of therapy has been found to be successful in this disease.

At the present the only effective treatment is the proper administration of blood transfusions to alleviate the constantly recurring anemia. Fowler stated:

> Spleenectomy has been tried but is not followed by any lasting improvement. It resulted in a rapid and prolonged increase in the number of neucleated erythrocytes in the blood stream.[2]

There is quite a range in the degree of severity of the disease from those who require blood transfusions as often as once a week to those who rarely need transfusions. Some children die within a few years and others are known to be alive in their twenties.

There is no known cure. In some cases doses of folic

---

[1] Ibid., p. 3.

[2] Willis M. Fowler, Hematology (second edition; New York: Medical Book Department of Harper & Brothers, 1949), pp. 215-216.

acid have helped to space the transfusions further apart. Basic research on the problems of blood formation and destruction offers the only hope available to these children.

IV. PROCEDURE

A review was made of pamphlets and articles secured from the Cooley's Anemia Blood and Research Foundation for Children, Incorporated, Medical Journals, periodicals and other literature were read. Interviews were held with a doctor and teachers who have had contact with children with Cooley's anemia. A questionnaire was prepared, validated by presentation to a physician, and distributed to the parents of these afflicted children. Another questionnaire was formulated, validated by presentation to the same physician as was the first questionnaire, and distributed to educators working with these children. Two case studies, obtained from parents of children who are living in Des Moines, Iowa, were reported. The analysis from the data was made from an educational standpoint rather than from a medical viewpoint. The summary and recommendations were made on the basis of the data gathered and compiled.

CHAPTER II

REVIEW OF THE LITERATURE

Since Cooley's anemia is a rare type of blood disorder, information on the subject is not prevalent. The best and most recent material available came from the Cooley's Anemia Blood and Research Foundation for Children, Incorporated. It was established June 10, 1954 in Brooklyn, New York by Frank Ficarra and a small group of people who shared the many common problems which confront persons having Cooley's anemia. Realizing the importance of helping these children to live as normal as possible the Foundation set up the following purposes.

a. To promote the cure and alleviation of the condition of children suffering from Cooley's anemia and allied diseases.
b. Research on the causes and cure of such blood diseases.
c. The training of competent personnel to aid in the cure, care, education, adjustment and rehabilitation of children suffering from such diseases.
d. The training, vocational guidance and occupation placement of children suffering from such diseases.
e. Adjustment to normal living of children suffering from such diseases.
f. The dissemination of information with respect to such diseases and the programs for the benefit of children suffering from such diseases.
g. As a non-profit tax-exempt corporation to receive by gift, devise, bequest, etc. money or other property, etc. for promotion of the foregoing purposes.[1]

---

[1]Silik H. Polayes, M. D. and others, "Replica of Scientific Exhibit on Cooley's Anemia" (New York: Sponsored by Cooley's Anemia Blood and Research Foundation for Children, Inc., September 9-15, 1962), p. 1. (Mimeographed.)

One of the latest methods employed to inform the public about Cooley's anemia is a film entitled "Blood is My Life." It is available from the Foundation to any group or organization on a lending library basis. This film shows actual children with the disorder and tells how their lives are made as nearly normal as possible. It explains that some children are able to attend school, some have special tutors, and some attend special classes. Lee and Lee stated:

> One of the greatest contributions the school can make to a child is to promote his present health and send him out with proper habits and attitudes for protecting and maintaining that health for the rest of his life.[1]

The film also depicts the many hours parents spend in the hospital at each time of transfusion. Foster reported:

> Since the child's attitude toward his handicap will be based on the example of those he sees about him, the importance of knowing as much as possible about the feelings of the parents should not be overlooked.[2]

The modern school attempts to educate the whole child and all information regarding each individual is important to both parents and teachers. Lee and Lee said:

> The school has two major responsibilities. First and most important is the school situation itself because of its widespread influence. It must be so set up

---

[1]J. Murray Lee, and Dorris May Lee, The Child and His Curriculum (New York: Appleton-Century-Crofts, Inc., 1940), p. 489.

[2]Andrew A. Foster and Others, Currents in Public Health, III (March 1963), p. 1.

> as to administration, curriculum, staff, and home and school relationships, that it will further good adjustment and desirable personality habits and attitudes. The second responsibility is to study systematically all pupils so that those who are sufficiently maladjusted to need special attention may be found.[1]

To help the school learn the special needs of the individual child, Tenny suggested:

> Shortly after the child enters school an interview takes place between the parent and the teacher . . . . Through this contact the teacher learns and records significant facts about the child's home background and family relationships, his developmental history, his preschool interests and experiences, the problems that he has presented at home, and what his parents hope he may gain from his school experiences.[2]

This interview would be most helpful to both parents and teachers so that from the beginning a mutual understanding between the home and school is developed and proper placement can be determined before the child enters school.

Lee and Lee asserted:

> School can be the most fascinating thing in the child's life.[3]

This initial interview can make a great deal of difference as to whether the child will like school and whether or not he will meet success in the classroom. Zyve and MacDonald stated:

---

[1]Lee and Lee, op. cit., p. 89.

[2]John W. Tenny, "Caring for Physically Handicapped Pupils in Regular and Special Classes," National Elementary Principal, XIX, No. 6 (July, 1940), 483.

[3]Lee and Lee, op. cit., p. 3.

> Adequacy in meeting life is affected by the community. It means that teachers, parents, and children understand each other's viewpoints on social and educational problems. Sympathetically, thoughtfully, cooperatively, they work together to the end that there shall be no disintegrating breach between the school and the community.[1]

In many cases the child with Cooley's anemia has low vitality only, therefore, Kirk stated:

> Children so affected do not have more learning disabilities than normal, nor do they require different curriculums or special methods of instruction since they learn like other children. Organization of schools and classes for them is primarily to facilitate health and to adapt instruction to reduced strength, energy, or motivation and to personality factors. The large majority of such children can be enrolled in the regular grades.[2]

It is the investigator's hope that this report may be, in some small way, a bridge between the home and school; that through the school, the child with Cooley's anemia may pass from childhood into a useful and happy citizen of tomorrow.

Hence, as a result of this review of literature, the investigator has included questions regarding hours spent in the hospital at the time of transfusions, pre-school conferences, children's and Parent's attitudes toward this problem,

---

[1]Claire T. Zyve and Carolyn MacDonald, Willingly To School (New York: Round Table Press, Inc., 1934), p. 10.

[2]Samuel A. Kirk, Educating Exceptional Children (Boston: Houghton Mifflin Co., 1962), p. 281.

and the kinds of schools physically handicapped children attend. This review served as a basis for the questionnaires that were formulated and sent to parents and educators who are living and working with these children.

CHAPTER III

CASE STUDIES

The two case studies reported here are the only two found in Des Moines, Iowa. They are brother and sister and extensive records have been kept because of their rare conditions. The information reported was given in an interview with the children's parents, Mr. and Mrs. Mathew Carmosino of Des Moines, Iowa. These case studies, as well as the review of literature, served as a basis for the investigator's questionnaire.

I. MICHAEL

Michael was born in 1955. His birth was normal as was his first fourteen months of life. His sister was born in 1956. She was jaundiced at birth but appeared to be normal a week later. She spent much time crying and all the family had many sleepless nights. At the end of three months she was taken to a specialist. Many tests were taken and her condition was diagnosed as Cooley's anemia.

After examining his sister, Michael was examined and was found to have the same blood condition. Samples of blood from both parents were taken so as to determine the severity of the condition. The tests showed that both parents had

this same trait, thereby making the condition in the children the major type of Cooley's anemia or Thalassemia major. The only inkling that anything might be wrong with Michael was that during his first winter he had influenza; after this illness he did not seem to regain his health. At that time he did become a little anemic which seemed normal under the circumstances.

His first transfusion was given October 2, 1956, and up to the time of this study has received fifty-five transfusions. He had a spleenectomy at the age of two years, three months.

As Mike grew older, the day to begin school was now approaching. Michael's parents were faced with the problem of which school to send him to. They had three alternatives--a public school near them, a school for the physically handicapped which was across town, or a parochial school in their neighborhood. They discussed this situation first with the doctor who seemed to feel that probably the school for the handicapped would be best for him. Bus transportation to this school would be provided by the school. The next step was to contact the public school which was only a half-block away. An interview was held among both parents, the principal and the school nurse. An understanding was reached whereby the parents would let the school know any vital health information and the school would notify the parents if any

noticeable fatigue was shown. They decided, also, as the time approached when another transfusion was required, and if Michael seemed especially fatigued the mother would be notified and he would be permitted to leave early. After this interview, the parents felt it was worth a try to send their child to this regular public school which was so close by and where there was such an understanding between the home and the school.

This arrangement worked very well the first year of school--which was Kindergarten. He attended school only half days anyway, but there were a few instances when he did come home early.

First grade presented a new challenge to both the parents and the school. The same arrangements were made although now he had another teacher. The first grade teacher agreed to do as the kindergarten teacher had done.

After a few months, Michael's parents and teacher noticed his enthusiasm for reading had increased while that of arithmetic had decreased. After discussing this with his teacher, it was noted that arithmetic came around 11:00 a.m. Michael seemed hungry. Because the school had a cafeteria, milk was readily available, so as his classmates went out for recess at 10:45, Michael went to the cafeteria for a milk break. In this way he was not using up energy playing outside, and was able to increase his energy by having this

milk. Needless to say, his interest in arithmetic improved considerably.

Michael had frequent colds and missed sixty days of school in first grade. His most serious illness was the measles which sent him to the hospital for a two week stay. He was able to keep up in his work due to the efforts of his mother who received instructions from his teacher. The mother was able to get some help from his aunt who taught first and second grades.

There were several days in which Michael had to come home early, and those days he fell asleep soon after his return home. Some characteristics his teacher noticed when his blood count was low were the chewing of his pencil, the sucking of his thumb, and the twirling of his hair. These were signs she looked for to know that his energy output was at a minimum and that he was due for a transfusion soon.

The year in second grade was much the same as the first year because he had the same teacher. She provided the milk break as in first grade and watched for the same signs as in the previous year.

At the time of this study, Michael is in third grade. He still has a milk break, and still has the arrangement with his new teacher, to come home early if fatigued. His favorite subject is reading, and his least liked one is arithmetic.

The parents have felt the school has been most

generous in providing for the individual difference this child has. The principal, nurse, and teachers have helped Michael to have a fuller and richer school life by making his days there pleasant and profitable.

II. CAMILLE

Camille is Michael's sister, and it was through her that Michael's condition was discovered. Her jaundice at birth, and her constant crying led the parents to believe that something was not right. After extensive tests Camille was diagnosed as having Cooley's anemia or Thalassemia major.

Camille was normal in every other way excepting for the fact that she did not walk very soon. Her stomach kept increasing in size thereby throwing her off balance. Her doctor consulted with other medical doctors and a surgeon who suggested that a spleenectomy might make her more comfortable. It was stressed over and over to the parents that this would not cure Camille's condition, but would give her relief. Surgery was performed when she was twenty months old. Up to that time she had not been able to walk. Upon returning home she soon began pushing her buggy around and imploring people to walk with her. Shortly thereafter, she began walking on her own. She still required transfusions, but the removal of the spleen did space them farther apart for a year or two.

As Camille reached her fifth birthday (much to the surprise of everyone) the school problem had to be faced. Parents had another pre-school interview. It was with a grateful heart that they were able to ask the school again to make provision for this child, too.

Camille's way had been paved by Michael's earlier journey, so both she and her parents and teachers knew what to expect. The same milk break was provided for Camille so they had it together. Up to this time, she has had forty-eight transfusions.

Parents in the immediate community are aware of the children's condition and have discussed it with their children. This has made for greater understanding on the part of both children and adults to help those who need help, and by being kind to all people. Therefore, although almost everyone knows about their condition, no one tries to make a big issue of it.

Camille is now in second grade. She had a serious case of strep throat and bladder infection in first grade which caused her to miss thirty-six days of school. Her mother did considerable home tutoring with her, helping her to keep up with the class so she would not lose interest upon her return to school.

Camille's favorite subject is arithmetic whereas reading is her least liked subject. Her parents feel that

because of the understanding by all school authorities concerning Michael's entrance and progress, Camille's days at school have made her an almost normal and happy girl.

CHAPTER IV

ANALYSIS OF DATA

To determine how people in the United States were educating their children with Cooley's anemia, the investigator contacted the Cooley's Anemia Blood and Research Foundation for Children, Incorporated. A list of members was obtained and a questionnaire was devised, validated by presentation to a physician, and sent to parents having these afflicted children. It was originally thought that only the questionnaires from the mid-west would be considered and analyzed, but due to the fact that there was only a thirty-five per cent return, it was decided that questionnaires from all parts of the United States would be analyzed and included in the data. Chapter IV will contain a report on those data.

The main purpose of the questionnaire was to see what different kinds of schools these children were attending and how their individual differences were being met by the school.

Since many of these children meet death at an early age, the first information sought was the age of the child at the time of the study.

The reported ages were:

Age	Per Cent	Number
4	3.4	1
5	3.4	1
6	6.9	2
7	6.9	2
8	6.9	2
9	10.3	3
10	6.9	2
11	24.2	7
13	6.9	2
15	3.4	1
16	3.4	1
17	6.9	2
18	3.4	1
21	3.4	1
25	3.4	1
Total	100.0	29

The mean age of the group was eleven years and three months, and a median age of eleven years and eight months.

At the time of this study the grade placement was:

Grade	Per Cent	Number
1	10.3	3
2	6.9	2
3	6.9	2
4	10.3	3
5	3.4	1
6	10.3	3
7	3.4	1
8	3.4	1
9	6.9	2
11	6.9	2
12	3.4	1
College	3.4	1
Class for Mentally Retarded	3.4	1
No reply	20.7	6
Total	100.0	29

The median school grade placement was seventh grade.

The age at which the child was diagnosed as having Cooley's anemia was as follows:

Age	Per Cent	Number
At birth	3.4	1
2 months	3.4	1
3 months	17.2	5
6 months	13.8	4
8 months	3.4	1
9 months	3.4	1
11 months	3.4	1
1 year	13.8	4
15 months	3.4	1
16 months	3.4	1
2 years	20.7	6
3 years	3.4	1
8 years	3.4	1
No reply	3.4	1
Total	100.0	29

The median age at which the illness was diagnosed was eleven months.

The problem of where to educate children with this type of anemia is one of the first and most important questions parents have to face. With this thought in mind, the next information analyzed was concerning school enrollment.

Sixty-two and one-tenth per cent of the parents talked to school authorities before entering their children in school. Thirty-four and five tenths per cent did not have a conference and 3.4 per cent gave no reply.

Thirteen and eight tenths per cent considered placing the child in a school for the physically handicapped whereas 79.3 per cent did not. Six and nine tenths per cent did not reply.

There were 10.3 per cent enrolled in a school for the physically handicapped and 13.8 per cent who were not. Seventy-two and four-tenths did not reply to this question.

There were 10.3 per cent enrolled in a school for the physically handicapped and 13.8 per cent who were not. Seventy-two and four-tenths did not reply to this question.

Seventy-nine and three tenths per cent of the children were reported enrolled in a regular school and 20.7 per cent did not reply to this question.

Six and nine tenths per cent of the children were being tutored at home by a bedside teacher provided by the school whereas 82.8 were not, and 10.3 per cent of the respondents did not answer this question.

Ninety-three and one tenth per cent of the children were not being tutored by a private teacher, financed by their own families. There were no children who were receiving this kind of tutoring. Six and nine tenths per cent gave no reply.

The parents of 89.7 per cent of those reporting felt that their children were accepted by the school; 10.3 per cent did not fill out this section.

Fifty-eight and six tenths per cent of the children did go half days during their kindergarten year whereas 17.2 per cent did not and 24.1 per cent gave no information on this point. Sixty-five and five tenths per cent of the children were able to attend school all day in first grade, but 13.8 per cent were not and 20.7 per cent did not respond to this query.

Thirty-seven and nine tenths per cent of the children stayed home half days shortly before a transfusion whereas 48.3 did not find it necessary. Thirteen and seven tenths did not give any information on this subject.

Of the parents reporting, 24.1 per cent were able to arrange the transfusions on Saturdays so as not to miss any more school than is necessary and 51.7 per cent were not able to make this arrangement. Twenty-four and one tenth per cent did not give a reply.

The school nurses make special exceptions for 27.6 per cent of these children; no exceptions were made for

58.6 per cent. There was no response from 6.9 per cent of those reporting.

A milk break was provided for 37.9 per cent of the children, and a break was not provided for 51.7 of them. Ten and three tenths did not give a reply.

One of the main concerns of parents is how actively their children should participate in sports. Parents reported sports participation in this manner:

Sports Participation	Per Cent	Number
All sports	31.0	9
No sports	6.9	2
Most sports	3.4	1
No strenuous sports	3.4	1
Child avoided baseball	6.9	2
Child avoided ice skating	3.4	1
Child avoided climbing bars	3.4	1
Child avoided tumbling	3.4	1
Child avoided football	13.8	4
Child avoided bicycle riding	6.9	2
Child avoided running games	17.5	5
Total	100.0	29

The investigator found that according to parents, 75.9 per cent of the children liked school whereas 19.3 per cent did not, and 13.8 per cent gave no reply.

There were 27.6 per cent of the children who had to repeat a grade and 58.6 per cent who did not, whereas 13.8 per cent were unreported. Of the parents reporting, 17.2 per cent felt that the retention was due to excessive absences, but 27.6 per cent did not, and 55.2 per cent did not give any information on this subject.

To ascertain the kinds of schools the children were attending, the following information was obtained:

Kinds of Schools	Per Cent	Number
Regular Schools	82.8	24
Physically Handicapped Schools	6.9	2
No reply	10.3	3
Total	100.0	29

Emergency measures in the schools were reported in this manner:

Emergency Set Up	Per Cent	Number
Ambulance Service	6.9	2
Emergency transfusions	0.0	0
No ambulance service	82.8	24
No response	10.3	3
Total	100.0	29

There was a doctor on duty in 13.8 per cent of the schools reported, but there were none on duty at 65.5 of the

schools. Twenty and seven tenths per cent did not report on this subject.

There was a nurse on duty in 55.2 per cent of the schools while 17.2 per cent of the schools did not have one, and 20.7 per cent did not reply. In the event that a nurse was not at school, 24.1 per cent of the schools did have a teacher responsible for emergency cases. Of the schools reporting, 20.6 per cent stated they did not have any one responsible and 55.2 and 2.10 per cent did not give a reply.

Bed rest was provided at 20.7 per cent of the schools, but 69 per cent did not provide bed rest and 10.3 per cent did not respond to this information.

To obtain information concerning the specific and general health of the children, this knowledge was obtained.

It was of interest to note that 29.6 per cent of the parents had other children with this type of anemia, whereas 79.3 did not. There were 55.7 per cent who had some children without Cooley's anemia, while 37.9 had only children with Cooley's anemia; 19.3 per cent did not respond to this question.

Cooley's anemia was detected through another disease in 10.3 per cent of the cases, while 86.2 per cent reported it was not thus detected; 3.4 per cent did not reply. It was learned that thirty per cent of the children had a spleen-

ectomy before entering school, while 58.6 per cent did not and 10.3 per cent did not answer.

In reply as to how often their child had transfusions, parents reported in this manner:

Frequency of Transfusions	Per Cent	Number
Every month	3.4	1
Every two months	6.9	2
Two to five months	10.3	3
Three to five weeks	3.4	1
Four to five weeks	10.3	3
Four to six weeks	3.4	1
Every six to eight weeks	13.8	4
Every seven to eight weeks	13.8	4
Every twelve weeks	3.4	1
Four or five yearly	3.4	1
No reply	27.6	8
Total	100.0	29

Of the replies received 6.8 per cent of the parents said their children sucked their thumbs before a transfusion, while 82.8 per cent did not and 3.4 per cent did not answer.

Play was restricted for 55.2 per cent of the children before entering school, but it was not restricted for 37.9 per cent of the children. Six and nine tenths per cent did

not give any information on this subject. Ninety-six and six tenths per cent of the parents reported that their children did not suck their thumbs before entering school while 6.9 per cent said their children did.

To discover facts which are important in making a school day pleasant and profitable for children, the writer sought these facts from parents concerning the child's entrance in school:

Age Child Entered School	Per Cent	Number
Four years, nine months	3.4	1
Four years, ten months	3.4	1
Five years	62.2	18
Six years	27.6	8
Eleven years	3.4	1
Total	100.0	29

In listing the subjects the children liked best, it was found that 3.4 per cent liked writing, health, art, gym, religion, poetry, and social studies best. Six and nine tenths per cent liked history best; 17.2 per cent listed science and arithmetic as best liked subjects. Spelling was reported as the favorite subject of 10.3 per cent, while 6.9 per cent listed reading and all subject as favorites.

The subjects least liked were social studies, reading,

geography, and English by 6.9 per cent of those reporting. Arithmetic was least liked by 20.7 per cent. Citizenship, spelling, history, science, and no subject was mentioned by 3.4 per cent on the parents.

Oftentimes, children lose interest in school if they are absent frequently. Absence was not as prevalent as one might expect as shown in these findings:

Days Children Missed	Per Cent	Number
One to 2½ days per year	13.8	4
Twelve days per year	3.4	1
Twenty-seven days per year	6.9	2
Fourteen to eighteen days per year	3.4	1
Five to six days when ill	3.4	1
Perfect attendance	17.7	5
No reply given	51.7	15
Total	100.0	29

To obtain a more complete picture of the school situation, a second questionnaire was formulated and sent to educators who were working with these children. Replies came from various people working with these children in the schools as shown in these results:

Educators	Per Cent	Number
Teachers	36.4	4
Principals	9.1	1
Nurses	27.2	3
Director of Pupil Personnel Services	9.1	1
Coordinator of Health Services	9.1	1
Not identified	9.1	1
Total	100.0	11

Specific information regarding special provisions made for this child was recorded. Eighty-one and eight tenths per cent of the educators reported they had a child at their school who had Cooley's anemia. Eighteen and two tenths per cent replied they did not. Thirty-six and four tenths per cent were working with this child in the classroom, while 45.5 per cent were not working specifically with this child, but did come in contact with him at school. Eighteen and two tenths per cent did not reply to this question.

Of the educators who reported, 45.5 per cent said that the parents contacted the school before entering the child in school while 27.3 per cent did not; 27.3 per cent did not reply to this query.

Eighty-one and eight tenths per cent reported that the

children were accepted by other children, and 18.2 per cent did not reply.

Twenty-seven and three tenths per cent indicated that these children stayed home shortly before a transfusion, and 45.5 per cent did not, whereas 27.3 per cent did not respond. Seventy-two and seven tenths per cent reported that nurses did not make any special exceptions for this child while 27.3 per cent did not reply.

Thirty-six and four tenths per cent replied that a milk break was provided for this child at mid-morning and 36.4 per cent responded negatively. Twenty-seven and three tenths per cent did not answer this question at all.

The reports of thirty-six and four tenths per cent did not answer this question at all.

The reports of thirty-six and four tenths per cent of the educators showed that the children participated in all sports, whereas 45.5 per cent said they did not. Eighteen and two tenths per cent did not reply.

Seventy-two and seven tenths per cent felt the child liked school, and 9.1 per cent did not.

Eighteen and two tenths per cent did not reply to this query.

Eighteen and two tenths per cent responded that this child had to repeat a grade and 54.5 per cent replied negatively while 27.3 per cent did not reply. Nine and one tenths per cent felt that this retention was due to excessive

absences, while 9.1 per cent did not; 81.8 per cent gave no reply.

Nine and one tenth per cent said that this child did carry an identification of some kind stating his blood type and disease and 54.5 per cent replied negatively. Thirty-six and four tenths per cent did not answer this question at all.

The educators were asked to give specific information about the kinds of schools in which they and the child with Cooley's anemia work. The following indicates the kinds of schools:

Kinds of Schools	Per Cent	Number
Classes for physically handicapped	9.1	1
No classes for the physically handicapped	72.7	8
Did not reply	18.2	2
Total	100.0	11

The provisions made for emergencies in the schools were reported in this manner:

Emergency Provisions	Per Cent	Number
Emergency transfusions	9.1	1
No emergency transfusions	81.8	9
Did not reply	9.1	1
Total	100.0	11

Ambulance service was provided in these ways:

Ambulance service	Per Cent	Number
Ambulance service by the school	27.3	3
No ambulance service	63.6	7
City ambulance service	9.1	1
Total	100.0	11

Seventy-two and seven tenths per cent were working in a public school, whereas 9.1 per cent were not, and 18.2 per cent did not answer this question at all.

Twenty-three and three tenths per cent revealed that the schools received financial aid from public funds and 45.5 per cent said they did not, whereas 27.3 per cent did not reply. One educator reported that his school had a contract with the County Vocational and Educational Board.

Twenty-seven and three tenths per cent answered that there was a doctor on duty in the school, and 63.6 per cent replied negatively whereas 9.1 per cent did not give a reply. Seventy-two and seven tenths per cent revealed that there was a nurse on duty in the school, and 18.2 per cent indicated no nurse, whereas 9.1 per cent gave no answer.

Thirty-six and four tenths per cent replied that there was a teacher responsible in the event of an emergency, and 9.1 per cent replied there was no responsible teacher, while 54.5 per cent gave no reply.

The educators stated that when the child had not been in a regular physical education class, 9.1 per cent had the child observe or spend some time in the library or take part in less strenuous activities. Eighteen and two tenths per cent revealed that no provisions were made for him during this time.

CHAPTER V

SUMMARY AND RECOMMENDATIONS

I. SUMMARY

It was the purpose of this study to determine, if possible, (1) how many children in the United States have Cooley's anemia, (3) to find out how many are attending school in regular classrooms, (4) to ascertain what measures have been made to accommodate these children in either school.

Since Cooley's anemia is a rare type of disease, the literature to be reviewed was very limited. The Cooley's Anemia Blood and Research Foundation for Children Incorporated was contacted, and a list of members was received along with recent pamphlets on the subject.

The investigator, by means of a questionnaire sent in January to the parents of the children listed by the Foundation, gathered data concerning the health and education these children were receiving. In February, questionnaires were sent to the educators who were working with these children.

There were ninety-two questionnaires sent to parents all over the United States. Fifty of these inquiries were unanswered. Thirteen were not used because the respondents did not wish the school contacted. From the twenty-nine

replies it was noted that parents were very sensitive to the health problem which they and their children faced. This fact may have been part of the reason that many of the questionnaires were unanswered.

It was also apparent that those replying, although a little reluctant to give out any information, were willing to share their experiences and problems with another who was interested in the numerous problems which they face.

It was evident that for every case reported, the illness was at a different stage for each. The severity of each case varied from individual to individual so that each child was handled according to his own particular needs. The spacing of transfusions was very different for almost every case.

According to the parents' questionnaire, the twenty-nine children ranged in age from four to twenty-five, with a mean age of twelve years, three months, and a median age of 11.8 years. The median school grade placement was seventh; the median age at which the illness was diagnosed was eleven months.

Most of the parents had enrolled their children in regular schools, had talked to school authorities before entering their children, had not considered placing the children in schools for the physically handicapped, and had felt the children were accepted by the schools.

More children had gone to school the half day before a transfusion than those who had stayed home. Transfusions, in most cases, came on school days. School nurses had made no special exceptions for the children.

Most of the children had not had milk breaks during the school day. As to sports participation, most of the children had avoided some of the more strenuous sports, but nine of the twenty-nine had participated in all sports.

In most of the schools attended, there was no ambulance service and no doctor in attendance, although there was a nurse on duty. Bed rest was not usually provided.

Most of the parents reported no other children in the family with the anemia. Thirty per cent of the children had had a spleenectomy before attending school. The median frequency period for transfusions was every six to eight weeks. Most children had not sucked their thumbs either before entering school or before a transfusion.

Most children had entered school at five years. Of the school subjects liked best, science and arithmetic, each listed in 17.2 per cent of the cases, was most indicated. On the other hand, arithmetic was reported as least liked, also, by the most, 20.7 per cent.

Over half the respondents did not indicate number of days of school missed, but of the ones reporting, the median days fell between "twenty-seven days per year" and "fourteen to eighteen days per year."

In the report of educators, only 81.8 per cent indicated they had a child with the ailment in their schools. However, these educators had been determined from the listing on the parents' questionnaires.

Of the educators reporting, most said parents had contacted them prior to the child's enrollment, that the children were accepted by other children, that the children did not stay home prior to transfusions, that nurses did not make exceptions for these children, that the children did not participate in all sports, that the children seemed to like school, and that 72.7 of the children were attending regular schools. It was further reported that 81.8 per cent of the schools were not set up for emergency transfusions, that most of the schools had no ambulance service, that 63.6 per cent of the schools reported there was no doctor on duty, although there was a teacher responsible for emergencies in 36.4 per cent of the schools.

The educators stated that most of them did not make provision for the child during the physical education class period.

The main accommodations made for children with Cooley's anemia were: (1) a milk break provided in the morning, (2) home tutoring or homebound teaching provided for those who were unable to attend school in the regular classroom, and (3) for those who were unable to participate in gym classes,

library time was provided, and the child observed or participated in less strenuous sports.

II. RECOMMENDATIONS

On the basis and findings and conclusions of this study, the following recommendations are suggested:

1. That those parents having a child with Cooley's anemia have a conference with school authorities prior to his entrance to kindergarten.
2. That whenever possible the child remain in the regular school with normal children.
3. That schools set up area health classes for those with a limited amount of physical stamina such as any severe type of anemia, leukemia victims, and heart cases. These classes could be situated in the same schools that have classes for exceptional children.
4. That these children refrain from any physical contact sports in the physical education class.
5. That the Cooley's Anemia Foundation issue identification cards or medalions stating that the individual wearing or carrying such an article is a victim of Cooley's anemia.

BIBLIOGRAPHY

BIBLIOGRAPHY

A. BOOKS

Fowler, Willis M. Hematology. Second edition. New York: Medical Book Department of Harper and Brothers, 1949.

Kirk, Samuel A. Educating Exceptional Children. Boston: Houghton Mifflin Co., 1962.

Lee, J. Murray, and Dorris May Lee. The Child and His Curriculum. New York: Appleton-Century-Crofts, Incorporated, 1949.

Tenny, John W. "Caring for Physically Handicapped Pupils in Regular and Special Classes," National Elementary Principal, National Education Association of the United States. Department of Elementary School Principal. Yearbook, XIX, July, 1940.

Wintrobe, Maxwell M. Clinical Hematology. Fifth edition. Philadelphia: Lea and Febiger, 1961.

Zyve, Claire T, and Carolyn MacDonald. Willingly To School New York: Round Table Press, Inc., 1934.

B. PERIODICALS

Foster, Andrew A. and others. Currents in Public Health, III (March 1963), 1.

C. UNPUBLISHED MATERIALS

Lichtman, Herbert. "Cooley's Anemia." New York, 1963. (Mimeographed.)

Polayes, Silik H. M. D., and others. "Replica of Scientific Exhibit on Cooley's Anemia." New York: September 9-15, 1962. (Mimeographed.)

APPENDICES

APPENDIX A

PARENTS QUESTIONNAIRE

Name of Child _____

His present age _____ His present grade _____

Name of school child attends _____

Address of school _____

Teacher _____

At what age was your child diagnosed as having Thalassemia major or Cooley's anemia? _____

CHECK THE CORRECT ANSWER	YES	NO
Pre-school		
Do you have any other children with this type of anemia?	___	___
Do you have any children without Cooley's anemia or Thalassemia major?	___	___
Was this type of anemia detected through another disease?	___	___
Did your child have a spleenectomy before entering school?	___	___
Did your child play with all types of children in the neighborhood?	___	___
Was his play restricted?	___	___
Did he suck his thumb?	___	___
School Days		
Did you talk to school authorities before entering him in school?	___	

School Days	YES	NO
Did you consider placing him in a school for the physically handicapped?	___	___
Is he presently enrolled in a school for the physically handicapped?	___	___
Is your child presently enrolled in a regular school?	___	___
Is your child being tutored at home by a bedside teacher provided by the school?	___	___
Is your child being tutored by a private teacher and financed by your own family?	___	___
Did the other children accept him at school?	___	___
Did he go half days during his kindergarten year?	___	___
Was he able to attend school all day in first grade?	___	___
Did he ever stay home half days shortly before a transfusion?	___	___
Are you able to arrange the transfusions on Saturdays so as not to miss any more school than is necessary?	___	___
Has your child had these childhood diseases?		
Chicken pox	___	___
Measles	___	___
Mumps	___	___
Scarlet Fever	___	___
Strep Throat	___	___
Does the school nurse make any special exceptions for him?	___	___
Is a milk break ever provided for him at mid-morning?	___	___

	YES	NO
Does he participate in all sports?	___	___
Does he participate in some sports?	___	___
Does he like school?	___	___
Does he suck his thumb occasionally yet?	___	___
Has he had to repeat any grade?	___	___
Do you feel this was due to excessive absences?	___	___
Do you feel that your child is aware that he is any different than any other child?	___	___
Does he wear any identification tag stating his blood type and disease?	___	___

Transfusions

Is your child receiving blood from a community blood bank?	___	___
Is your child receiving blood from the Cooley's Anemia Blood and Research for Children, Inc.?	___	___

Types of Schools

Is your child in a public school for the physically handicapped?	___	___
Is your school set up for emergency transfusions?	___	___
Does your school have ambulance service for emergency cases?	___	___
Is there a doctor on duty in your school?	___	___
Is there a nurse on duty in your school?	___	___
If there is neither, is there a teacher responsible for emergency cases?	___	___
Is bed rest ever provided for your child at school?		

Other Information

At what age did your child enter school? _____

What sports, if any, does he refrain from playing?

_____

What subject does he like best? _____

What subject does he like least? _____

Does he suck his thumb shortly before a transfusion? _____

On the average, how many days a week of school does he miss? _____

How often does he have transfusions? _____

Any other comments? Use the back if necessary.

APPENDIX B

EDUCATORS QUESTIONNAIRE

Name _____

Position _____

School _____

PLEASE CHECK THE CORRECT ANSWER	YES	NO
Do you have a child at your school who has Cooley's anemia or Thalassemia major?	___	___
Is this child in your room?	___	___
Did the parents contact the school before entering the child?	___	___
Do the children accept him at school?	___	___
Does he ever stay home shortly before a transfusion?	___	___
Does the school nurse make any special exceptions for him?	___	___
Is a milk break ever provided for him at mid-morning?	___	___
Does he participate in all sports?	___	___
Does he seem to like school?	___	___
Has he had to repeat any grade?	___	___
Do you feel this was due to excessive absences?	___	___
Is there a nurse on duty in your school?	___	___
Does he wear any identification tag stating his blood type and disease?	___	___
Does this school have any classes for the physically handicapped?	___	___

	YES	NO
Is this child enrolled in one of these classes?	___	___
Is this a public school?	___	___
Is your school set up for emergency transfusions?	___	___
Does your school have ambulance service for emergency cases?	___	___
Does your school receive any financial aid from any public funds?	___	___
Is there a doctor on duty in your school?	___	___
If there is neither, is there a teacher responsible for emergency cases?	___	___
Is bed rest ever provided for this child at school?	___	___

If this child is not in regular physical education classes, what provisions are made for him during this time? _____

If you have any other comments, please use the space below.